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EDITOR'S NOTE

This English translation has not been published in printed form/Cette traduction anglaise n'a pas été publiée sous forme imprimée.

1 A shift in thinking is required in our questioning of the patient's role in public space and the visibility and construction of "disease". With a focus on the "patient" rather than on other health sector actors such as scientists, researchers, doctors and specialists, the objective of this volume is to consider and analyse in depth the trends in the disclosure of private life, the role of narratives and the "professionalization" of patients; all of which tends to undermine how this sector traditionally operates.

2 Hospitals are starting to give more recognition to patients by involving them in the organizational structure of the healthcare system; the government has made patients "actors in their health"; and patient associations are playing an increasingly significant role in the dissemination of information and defence of patients' interests or preventive action on their behalf. These are all recent developments. In the field of public health, up until the AIDS epidemic, patients were marginalized despite their central status. Today, as Janine Barbot (2002: 28) points out, patients and their associations "have changed" to the point that "the stakes and consequences of therapeutic activism has led to participation in redrawing the borders between science and public space". For the case of AIDS in particular (Barbot, 2002; Paicheler, 2002; Dodier, 2003), the last decade has been marked by the emergence of patient associations with whom the medical community must establish a dialogue. On this point, researchers are identifying the diverse forms of commitment – whether they be associative or "ordinary", and whether their objective is to make patients "active" in

their own disease management or to foster "therapeutic activism" through the implementation of "new forms of collaboration with public bodies" (Barbot, 2002: 281). As such, it has been observed that associations have gradually acquired a certain level of expertise and ongoing research has addressed the changing positions of associations with regard to the medical community. In relation to AIDS, the "line of attack" adopted by associations and the role that journals played in the public recognition thereof, contributed to "an opening up of the specialized world of controlled clinical trials" (Dodier; 2003: 204). However, it is unclear whether these changes are generally applicable to other diseases. From this perspective, the issue of cancer addressed in this volume of *Questions de communication* seems to be in contrary to that of AIDS. Associations with a presence in the sector are longstanding (The French Cancer League was founded in 1918), run by doctors or senior government officials and over time, have remain relatively close to the medical community; in a way, patient-doctor relations have been mediated by these associations. At the same time, the role of patients has been contained and their representation dependent upon the medical community itself.

3 In other respects, the main characteristic of the healthcare sector is its special emphasis on medical expertise and technification of knowledge, as well as its commoditisation of services, specialization of journalists, and involvement with national and local public bodies. In turn, this removes the conditions that are usually required for the constitution of public space (training, free flowing opinions, expressing contradictory viewpoints, debate and power relations), suggesting that the public sphere is viewed more as "an avoidance of the conflicting nature of debates" (Dodier, 2003: 264) than as "a health democracy". Thus, the concept of disease refers to the struggle by stakeholders to impose their interpretation of a social reality and its construction. Political stakes are high if a disease is to gain access to the public space (e.g. implementation of a public policy); in contrast, this aspect is exemplified by Hepatitis C of which "the history of its progression [in France] is one of a disease with no real identity" (Jouzel, Landel, Lascoumes, 2005: 203), whereas evidence in other countries suggests that the epidemic is visible in the various national public spaces.

4 In this context, the present volume covers three main themes: healthcare issues within public social space, data production and its associated constraints, and the individual and social relationship to disease.

The media: a challenge in public space governance

5 Two types of space co-exist within the healthcare field: the "public social" and the "specialist" and accordingly, a comparison can be drawn between these two worlds. To a large extent, the general media and the mainstream press are a driving force for the first, and the specialist media specific to the scientific community for the second. The study of the relationship between these two spaces – the public social space and the public scientific space – shows the latter's attempts to control the former. The ongoing challenge for scientists is public space governance in various forms: the framing of discussion, authority discourse and information literacy. The influence exerted by scientific institutions is particularly revealed by the way in which medical information is portrayed in the media. Most of the time, prior publication in a scientific journal acts as a kind of endorsement and is a prerequisite for dissemination in the media, or at

least, the legitimate selection procedures for scientific articles hold journalists' attention.

6 The media field is an important issue in public space governance. Indeed, some of the criticism that scientists direct towards the media and journalists can be seen as a refusal of the autonomy of this field: defamation as a preservation strategy. Nicolas Dodier (1999) highlighted these elements through scientific priorities and "the Cyclosporin-A" affair; the latter highlights the opposition between scientific institutions and the media, even though a divide exists within each category (*ibid*: 137). Entry into public space is a real challenge. It reflects "how established ethical and scientific institutions fight against the uncontrolled flow of information by scientific journals [that] marks the highly topical, but perennial movement aimed at delimiting (by specialist channels) communications in the public sphere" (*ibid.:* 42). The position of health in the public arena, strengthened by preventive action, the popular scientific press, the evolution of television programmes on health, or even the rapid development of Internet sites, does not automatically lead to the creation of a public health space. Such a space could resemble a "scientific public space [which] is fragmented, torn between divergent forces, and devoid of any major or legitimate authority to lead debate and shape public opinion" (Miège, *in*: Pailliart, 2005: 134).

7 Isabelle Pailliart's and Géraldine Strappazzon's contribution "Paradoxes in cancer prevention: publication and privatization", deals with the issue of patient objectification by showing that both at the national (presidentialization) and local (territorialization) level, political stakeholders are broadly seeking to control the communication issues at stake. The problem of a partial public space is the focus of Helena Sandberg's and Peter Dahlgren's contribution – "The media construction of obesity in the Swedish public space" – which is based on the need for collaboration between doctors, scientists and journalists to enable the construction of a real public space; one that does not exist today. In "Health on the television: an emergent social issue", Hélène Romeyer discusses the public health space through the evolution of French television programmes. Showing how these emissions have shifted towards a social model rather than a medical and scientific one, she outlines how health is emerging as a social issue.

From media autonomy to patient empowerment

8 When patients try to access public space they encounter media expectations from certain media fields that are also trying to break free from external constraints (those of the medical field): as a result, both the patient and the disease face multiple demands from the print and audiovisual media. This volume examines the dual movement of mutual constraints between the media and the medical community, and the media and the patient. In the medical field, growing media autonomy has been addressed notably by Patrick Champagne (in: Mathien, 1999). In his study on "Changes in scientific and medical journalism", Champagne shows the rapid development and specialization of medical information in the mainstream press that took place during the 1980s and 1990s. Even though, from the 1960s onwards, developments in the audiovisual media sector have given rise to numerous debates among doctors' professional organizations, the expansion of the highly profitable market of scientific information has fostered a structuring among scientific journalists and a definition of the main themes of this type

of information, to such an extent that many specialized medicine and health magazines are developing. In 1993, there were 400 medical magazines. The appearance of the AIDS epidemic simultaneously revealed, activated and accelerated this phenomenon. Finally, health became subject to calls for critical information, prompted by pressing requests from patients who were represented by the associations active in this field. Today, the media is more heavily involved in the functioning of social worlds that in the past were hard to access, such as that of health.

9 However, this gradual access to medical information in the media will not happen without power relationships. Indeed, it is built on the clash between scientific institutions and the progressive acquisition of autonomy by the media and journalism fields: a process in which the media is not a mere cog in the wheel for the scientific (or political) authorities, nor a mere public outlet for positions of interest or reflections of power relations. Television, "as an institution with its own value systems, and made up of actors who assume them, is not a mere carbon copy of social representations. Although rationality functions like a cultural matrix, it is only one part of televisual discourse that has its own form of autonomy" (Babou, 2004: 154-155). Therefore, the issue for the scientific and medical community, as well as for patients and their associations, is to arrive at a definition of mediatisation that meets their expectations.

10 In particular, the question of increased media autonomization has led to an examination of how television programmes help to introduce health issues into the public domain. The Telethon is one such example (Walter, 1998): by appealing to the generosity of individuals, it promotes reflexion on the role of the State, how individuals relate to the helplessness of others, the portrayal of suffering, or the role of narratives. Therefore, in the first place, this volume will discuss the Telethon from the perspective of its link to politics, television being seen as indicative of dominant trends in society. And this is how the Telethon event "questions three key elements of politics (Chambat, 1994): collective identity (national belonging), political participation [.], the population's political acumen (civic education: generosity as an alternative to protest or political debate; the overrated importance of experts)" (Walter, 1998:20).

11 More generally, the role of the media should be considered when questioning the construction of public issues, in which it is involved. On this subject, in Emmanuel Henry's discussion of asbestos, she notes that the basic requirement for journalists is to "construct issues in such a way that they attract the public's attention, and therefore, justify the attention that they [the journalists] are giving it" by different means such as constructing this issue as "a recurrent theme of day-to-day information" or "redefining it as a risk that affects everybody" (Henry, 2000: 564). Hence the "problematization" of situations that have long been out of the public eye raises questions about the role of the media, the professional strategies used by journalists, and the power relations between public or private organizations and the associations that defend collective interests. One example is the "contaminated blood scandal" that was presented as a social fact constructed by actors' different and conflicting interests. Thus, "characterization of the facts as "scandalous", far from being obvious and immediate, had been the result of a particular drawn-out struggle that lasted several months, putting into conflict the contaminated blood victims against the French state, the courts, journalists, then more specifically, medical and political journalists and finally, journalists between themselves" (Champagne, Marchetti, 1994: 43). The elaboration of

issues relies mainly on each field's given stance (political or media-related) and on the dynamic of these positions.

12 In "*Une rubrique 'à part'*", a special column covering "medical information from the post-war period to the early 1980s", Dominique Marchetti notes that medicine was a closed world of consensus representations, unlike today, where it is marked by the processes of "economisation", politicization and moralization of challenges. This quasi-consumerist attitude towards health is presented in Philippe Ponet's article "The rationales behind journalistic achievement. The case of 'the top 50 hospitals in France'". The author highlights new constraints that place a burden on hospitals required to conform to a three-fold rationale: (1) media – maintaining transparency, (2) economic – controlling expenditure and (3) technical – rationalizing healthcare practices. Finally, Leila Azeddine, Gersende Blanchard and Cécile Poncin analyze binding media logics in "Cancer in the mainstream press. Where do patients stand?".

Individual and societal relationships with disease

13 Individual and societal relationships with disease refer to the idea that singular patient-doctor consultations are more than just relationships and knowledge. They do not merely rely on a doctor's ability to demonstrate knowledge and people skills. An individual's relationship with a doctor is also linked to the latter's relationship with the medical sphere. As such, there is always an element of politics involved in the singular consultation (relating to public funding and policies). This is a social relationship because it also depends on the types of mediation present in doctor-patient and patient-disease relationships. Therefore, how patients search for information – in magazines, on Internet sites, from other patients – contributes to the change in these relationships with healthcare professionals. Through publications that are supported by associative and institutional actors, but also through the use of digital communication networks – forums, blogs, mailing lists –, patients from different disease backgrounds are voicing their opinions. This phenomenon has mainly been analyzed by Madeleine Akrich and Cécile Méadel (2002) during patient exchanges on medicines in e-discussion lists. Although these voluntary (through prior inscription) patient discussions express genuine opinions, their evanescence prevents forms of structured collective action. Furthermore, the themes discussed provoke more or less caustic criticism from the medical community: "Even though there is a general consensus regarding the treatment of cancerous tumours, this is not the case for the "side effects" of the disease, the effects of treatments (vomiting, pain) and also the effects of the cancer itself (fatigue, anxiety, etc.)" (Akrich, Méadel, 2002: 101-102). As such, patients become extremely knowledgeable about the treatment of their disease and "coping strategies". Indeed, individuals are acquiring a visibility whereas doctors are being questioned about their ability to integrate social demands (by establishing closer links with their patients). In this volume, two articles address these trends: Benoit Lafon discusses distant confrontation with cancer in "Prime Time Cancer. Emergence of a remote confrontation with the disease through television dramas". Antoine Spire and Rollon Poinsot cover diagnoses delivery in cancerology in "The problem of delivering a cancer diagnosis in cancerology". Whilst the first article considers television dramas to be indicative of a change in the relationship with the disease (individuals increasingly face this through *pretend play*), the second one shows

how, during therapy, doctors could put patients back at the heart of therapeutic actions by adopting a tailored approach. Finally, Philippe Bataille touches upon “Death, patients, close family and friends” in “A communication problem between the Ego, the Alter and the Other”, describing how diseases carry two burdens: “the legitimate fear of one day succumbing to the disease and the fear that this generates in others”. He shows the need to “admit that mortality is an integral part of existence” (Bataille, 2007: 1 56).

14 Finally, the themes addressed are all linked to the notion of human governance and “biopolitics” in the Michel Foucault (2004: 323) sense of the term. Foucault classed this as “the attempt, starting from the eighteenth century, to rationalize the problems posed to governmental practice by phenomena characteristic of a set of living beings forming a population: health, hygiene, birthrate, longevity, race ...”. Therefore, current transformations must be situated in the long-term and the issue of disease and the patient in public space can only be addressed within the framework of political rationality.

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